

Case Study

Condition based engagement: OPM-MEG Project at Young Epilepsy

1. What was the issue?

Through our research programme, we had already demonstrated that wearable sensors could be used for human neuroimaging. We had also shown these sensors outperform existing technology, and that high-quality data could be obtained even whilst the subject is moving.

This technology, which is based around Optically Pumped Magnetometers (OPMs), is exciting as it will allow us to ask neuroscience questions that have never been asked before. It is of real clinical importance as one of the main beneficiaries' groups will be young children, with epilepsy. The new technology will allow us to not only identify seizure sites non-invasively (replacing the need for invasive electrodes) but also perform essential pre-surgical planning tasks - like language localisation- even whilst the child is moving.

MEG technology is already proven and professionals, clinicians recognise it as reliable tool on which to base difficult decisions such as surgery decisions because of the richness and the reliability of that data it provides.

Unfortunately, existing MEG scans are big static machine and are quite inaccessible for children because they need to remain completely still, and in some cases need to be sedated. The wonderful thing about the OPM -MEG, is that subject to clinical evaluation, the child will be able to wear a lightweight helmet, go into a what feels like a 'normal' room and watch a video if they want to, do a jigsaw, or play a board game with mum or dad, whilst the scan is happening.

At the stage of embarking on this engagement, we had proven the equipment, software and technology within a controlled laboratory environment with compliant adult participants. In conjunction with our partners, Young Epilepsy was building its new shielded room within its new diagnostic suite, with the aim of providing the best patient journey. However, the main clinical challenge was always going to be to keeping young children comfortable and engaged within this environment whilst the scanning took place. It was therefore recognised we needed direct input from children to ensure this work area was properly designed. This included the design of the helmet, the interior of the room and identifying engaging and fun activities to pass the time.

2. Opportunities or limitations of activity?

At the time of scoping this project we saw an opportunity to apply for grant funding from the Wellcome Trust under their 'Public Engagement' funding stream and put in a very simply application which was successful, and we secured £55k. However, this did of course mean we were also bound by the terms of the application and timescales identified.

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However, shortly after the award of the funding Covid hit and whilst most things including this project activity stopped, the building of the room continued and this meant that once we were able to restart the actual design of the room was already well advanced and this item was taken out of the scope of the grant application and we had to request minor amendments to the approval to reschedule and focus on just the two elements of design of the helmet and the activity.

We were naturally limited to the staff resource we had within Young Epilepsy and UCL to run the project and could not have completed this without the wonderful input from the children and their parents/carers, as well as the enthusiastic volunteers who helped out at the online workshops.

3. Which children or young people?

Whilst the technology will be suitable for all ages from 0 to adults and at Young Epilepsy we focus on support for children and young people up to the age of 25, for the purposes of this project and associated workshops we focussed on the 5–8-year-olds.

4. Recruitment plan?

We recruited the children from a range of sources, including both mainstream and special schools. As well linking with other known sources of networks for children with epilepsy, including Young Epilepsy's own research participant group E-CURE. Nor would this project have been possible without the huge support from the youngsters parents/carers who agreed to act as facilitators.

We also sought volunteers from play therapists, residential support workers and other relevant staff to support the online workshops.

5. Barriers to engagement

Paramount in setting up the workshops was ensuring the health and wellbeing of the youngsters and of course the strong likelihood of a youngster having a seizure during one of the workshops and ensuring everyone was clear on how best to provide support to them if this occurred.

However, we also included all the other usual factors such as use of clear, simple language, no jargon, making things fun, as well as access to wi-fi and computer equipment to facilitate online sessions. Other factors considered were the best timings for families/schooling for the youngsters. Ensuring the parent/carer also fully understood their role as facilitators and didn't feel anxious themselves.

6. What do you (professionals) hope to achieve?

It is essential that we hear the views, and ideas from children and young people and to incorporate these, as far as is possible into our development plans to ensure this project is a success and that the final designs and systems used reflect the feedback from the children and young people to ensure we meet their views and aspirations as far as possible.

7. What do children /young people hope to achieve?

All the children, young people we spoke to were delighted to have their views actively sort and their voices heard. They wanted to share the things they least liked about undergoing an EEG, or MEG, investigation at the current time, and their aspirations for the new MEG technology. This included the views from the healthy cohort(s) as well as the most direct 'lived experience' from those who had epilepsy and their families.

8. How did you do it?

We held a series of online workshops and posted out posted out materials for the youngsters to get involved ideally by attending the workshops, but if not possible ensuring the instructions were clear enough for them to join in at their own pace.

We produced videos in house to best explain the project to children, trying to ensure this were produced in the same way as children's tv programme might be presented to maintain their interest and add the fun element. We also designed and produced journals for the youngsters to work their way through, and a separate one for the facilitator supporting them throughout the project.

All of this guidance was sent out the youngster in a specially designed kit of materials that included everything they needed to participate.

9. How will the outcome impact and shape service delivery or change?

The views and ideas coming from this project will be used to kit out the activity boxes provided in the OPM-MEG room at Young Epilepsy and also to inform the future design stages of the helmets as they move through the design progress.

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10. How will you evaluate, celebrate and share the input of children and young people?

The children who participated in the workshops were all thanked individually at the event and we promised to keep them in touch with the development and next stages of the project.

Each participant had a participant journal and their achievements recorded in photos and celebrated with stickers as each section was completed.

The online workshops were concluded with a virtual celebration of everyone's input and every participant received gift vouchers at the end of their involvement as a further thank you for their assistance.

The project is also due to be written up and published in due course and within this we will of course acknowledge the huge role the children and young people played in its success.

For more information go to <https://www.youngpilepsy.org.uk/for-professionals/health-services-at-young-epilepsy/meg.html>

RP 20.10.21